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Palliative care challenges: Implications for nurses' practice in renal settings

ABSTRACT

The very act of withdrawing dialysis places renal nurses in a unique practice setting requiring a sudden shift in care delivery from one of providing life-sustaining, active treatment to that of palliation. The impact of this act on the renal nurse remains largely invisible. Minimal research has been conducted that explores the significant issues and challenges that exist for renal nurses in the delivery of palliation following withdrawal of dialysis treatment. This paper attempts to highlight the issues and challenges that do exist for renal nurses in providing palliation and the subsequent lack of available research knowledge to inform practice in the renal setting. It recommends further research be conducted into the renal setting so as to inform the development of appropriate education to support renal nurses practice in the future.

KEY WORDS

renal nursing;
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INTRODUCTION

In Australia over 12,000 people suffer with End Stage Renal Disease (ESRD) necessitating treatment intervention by either haemodialysis (6,812) peritoneal dialysis (5,466) or a kidney transplant (McDonald & Russ 2002). This is expected to rise as the prediction for the

Australian health care system is that the overall demand for palliative care will increase significantly due to our ageing population and associated prevalence of chronic and complex illness (AIHW, 2002). This sees the renal setting emerge as a new challenge in the provision of palliative care as the frequency of withdrawal

from dialysis is more likely to occur in people over 65 years of age and those who have co-morbidity of disease (Moss 2000, Bajwa et al. 1996). It is this group of people and their families, which renal nurses commonly face in providing palliation to in a relatively short time frame, that provide significant challenges in their practice. This paper attempts to explore the issues and challenges faced by renal nurses in the provision of palliative care and to make recommendations for future research and education.

In Australia during 2001, withdrawal of dialysis was the second leading cause of death and accounted for 22% of all deaths in people being treated for ESRD during that year (McDonald & Russ 2002). Frequently withdrawal of dialysis becomes an option for people whose life has become intolerable due to the multi-systemic effects of ESRD. Typically these effects are due to physiological complications such as cerebrovascular accidents, dementia, cachexia or malignancy (Leggat et al. 1997) rather than the psychosocial effects of having a chronic illness. In addition, dialysis access problems (e.g. clotted arteriovenous fistula), infections, limb ischaemia and unrelieved, severe pain can also be triggering events for the withdrawal of dialysis (Bajwa et al. 1996). Once the decision is taken by either the person receiving dialysis, their family or by health care professionals, death comes relatively quickly, and the average dialysis patient lives for six to twelve days after dialysis is withdrawn (Cohen et al, 2003; Moss 2000; Neely & Roxe 2000)).

Renal nurses play an important role in co-ordinating the delivery of care and the timing of palliative care provision, to people with ESRD (Kuebler 2001). They are often aware much earlier on than renal physicians that a person is contemplating, or even requesting, to stop dialysis treatment. This is due to the frequent and prolonged contact renal nurses have with people who are receiving dialysis therapy. Often, the renal nurse will initiate a family conference

bringing together members of the renal health care team, the patient and their family (Renal Society of Australasia 1999) to discuss the possibility of withdrawal.

RENAL NURSING

Renal nursing focuses on the health needs of individuals and their families who are experiencing a progressive decline in renal function or who have lost function completely (Stewart & Bonner 2000). Renal nursing necessitates that the nurse focuses on the provision of renal replacement therapy, teaching self-care, assisting individuals to make informed choices regarding the type and proposed location of therapy and the prevention of related illnesses or complications associated with renal disease (Parker 1998). Renal nursing care is frequently provided to people over many years (Parker 1998, Schardin 1995); a feature seen in only a few specialty areas of nursing. For instance, haemodialysis treatment offers renal nurses the opportunity to provide nursing care to the same patient and family for four to six hours, three times per week for as long as the patient remains on haemodialysis. This may equate to a relationship extending past 20 years. The degree of contact the renal nurse has in this setting with patients and family is similar to the contact other nurses have with people experiencing chronic illness, psychiatric disorders, diabetes, asthma or permanently disabling conditions. The prolonged contact with the same patient over an extended period of time provides the opportunity for the establishment of long-term relationships with the patient and family (Bevan 1998, Molzahn 1998, Pinkey 1996). For renal nurses the impact on them when treatment is withdrawn from patients is enormous and seriously under recognised. To date there has been minimal research into understanding the support needs of renal nurses working in this specific clinical setting during their care of the person who is dying and their family (Hine, 1998).

THE TRANSITION TO PALLIATIVE CARE

An alteration in the management of a person's disease from a medical perspective to one of providing symptom management and support to patient and family forges a paradigm shift to palliative care (Neely & Roxe 2000, Connolly 2001). This paradigm shift necessitates a change from disease management through interventions of a physiological nature to that of providing support and symptom management. This shift presents a significant challenge for nurses working with people who have ESRD, as nurses must move from the paradigm of providing acute, life prolonging maintenance treatments to promoting a quality death (Casey & Hodson 2003). This transition is often very confronting and the antithesis to expected renal nursing practice.

The withdrawal of dialysis treatment for people with ESRD places the renal nurse in a unique situation. The cessation of dialysis treatment signifies to all, the ending of life, the creation of a predictable death and the termination of long-term relationships. The physical symptoms inherent within a uraemic death, those shared commonly by all end stage organ disease (eg. pain, cachexia, dyspnoea) and the presence of any co morbidity, presents the renal nurse with many clinical practice challenges as they move swiftly from a maintenance role to one of palliation (Neely & Roxe 2000).

Cohen et al (1995) found one third of people who had withdrawn from dialysis treatment experienced an uncomfortable death related to the poor symptom management of their pain. Previously, Hinton (1963) found that the physical distress experienced by a person dying from ESRD is often greater than that experienced by people with cancer. In addition, Fakhoury and McCarthy (1998) suggest that people with chronic organ failure have greater physical discomfort than people who are dying with cancer. This evidence and the perceived lack of education provided to renal nurses about pallia-

tive care (Starzomski (1994), suggests they may be deficient in some of the necessary skills and lack confidence in providing nursing care to the person dying and their family. This places significant psychological demands on the renal nurses who are expected to rapidly shift from providing life-sustaining dialysis treatment to providing palliative care, an area not as familiar to them as their own speciality.

CHALLENGES FOR PALLIATIVE CARE IN RENAL SETTINGS

The provision of palliative care services to non-malignant disease tends to be incomplete, lacks uniformity and is often inaccessible (Higginson 1995). Traditionally, the focus for palliative care has been for people with malignant disease. Caring for people with end stage organ disease has not been the typical provision of palliative care services (Neely & Roxe 2000, Ferrell & Coyle 2001). Concerns are emerging that people dying from non-malignant disease are not receiving the symptom control and psychosocial support that the dying and their families require during the final phase of their life. Evidence now exists which recognises that people who reach end stage organ disease as well as those with cancer have similar needs during the terminal phase of their illness. This warrants exploration of the need to provide palliative care for people with either malignant or non-malignant disease (Connolly, 2001) within a range of health care settings. As a consequence of the increased prevalence of people dying in many health care settings and the continuing research into the needs of the person dying and their family, nurses are becoming more informed about the palliative care needs for a range of diseases.

Three factors significantly influence the provision of palliative care in the renal setting. They are: firstly, the location of death is usually in the acute hospital setting, which is typically a non traditional site for the provision of palliative care; secondly, funding for palliative care servic-

es is orientated towards cancer related diseases and thirdly, the withdrawal of dialysis triggers the need for palliation rather than palliation being integrated earlier on in the disease process. These factors therefore establish a need for renal nurses to be more appropriately skilled to provide care that meets the specific needs of the person dying and their family, following withdrawal from dialysis.

Renal nurses must be able to demonstrate a capacity to communicate with the patient and their family on issues related to the patient's fears and concerns about dying. Along side of these skills is a need to recognise that renal nurses have spent considerable time supporting the patient to have a quality of life while coping with the demands of a dialysis regimen (Noxe & Reely 2000). Further complexity is added because renal nurses have to shift from a paradigm of providing therapeutic treatment to one of palliation within a short time frame. The shift itself is triggered by the patient's request to withdraw from dialysis in full knowledge death will eventuate within 6–12 days. In other palliative care contexts the discussions surrounding end of life and its sequelae are often addressed over a much longer period of time allowing for the patient and family to be adequately prepared. This period of time offers nurses the opportunity to reconcile their own feelings about the impending death but this is not available to renal nurses due to the shortened time period. The impact on the nurse resulting from the shortened time period in which palliation is provided warrants further exploration.

IMPLICATIONS FOR NURSING PRACTICE, EDUCATION AND RESEARCH

Whilst many nurses acknowledge the need for effective communication skills in their practice, the current literature on palliative care demands that more emphasis be placed on this core skill in order to address the patient's and family's needs at a time of crisis and or transition (Pol-

lard & Swift, 2003). Typically, under-graduate nursing education prepares nurses with a beginning level of competence in communication. Further development in communication competence at the post-graduate level of education is not seen as a priority. Renal nurses have significant knowledge and experience in the management of renal failure but lack the necessary skills to confidently assess and explore the physical, psychosocial and spiritual concerns of the patient and their family during the palliative phase of the illness. Pollard & Swift (2003) suggest that the majority of communication interactions within the palliative care setting are ad hoc, incidental and lacking in purpose. What is advocated is that post-graduate education provides opportunities which allow nurses to further develop their communication skills in caring for the dying and their family. According to Cairns & Yates (2003) and Starzomski (1994), however, under-graduate nursing curricula needs also to include a significant palliative care component while subsequent continuing professional education programs, such as postgraduate renal nursing courses, must include a component on caring for the person dying and their family. In addition, information and strategies on how renal nurses can self care in this context is also a high priority that warrants inclusion in all three levels of nursing education.

The events leading to a person's death following the termination of dialysis are unique to renal nursing. The time from cessation of dialysis to death is significantly shortened, and the symptoms associated with this require nurses to have the capacity to assess and provide appropriate symptom management. The principles of palliative care have not been previously articulated in the delivery of nursing care in the renal setting (Starzomski 1994). Renal nurses need to know how to prepare themselves as well as the patient and family, to deal with the impending death. This requires the renal nurse to develop skills to be able to discuss with the

patient and their family concerns about their predictable death. Recognition is now being given which encourages renal nurses to seek ongoing education in palliative care so they feel better supported when providing care to the person dying and their family (Dutka 2002).

In the past, the use of palliative care teams in the renal setting have been limited but with an increasing number of people choosing to withdraw from dialysis the need to establish closer links with the palliative care team becomes paramount (Neely & Roxe, 2000). The shift to providing palliative care to people with non-malignant disease necessitates that nurses, who are working in non-palliative care settings, recognise their skill deficits in the provision of nursing care to the person dying and their family. Creating new pathways of care between the renal setting and palliative care experts is one way in which the core skills and knowledge of caring for the dying can be transferred to another discrete setting. Given the multiple and complex nature of symptoms which arise for a person following withdrawal of dialysis, the use of a multidisciplinary team facilitates management of these symptoms using, combined expertise and knowledge (Hine 1998). The provision of care in this manner affords the person and family the best opportunity to achieve optimal outcomes in relation to their symptom management.

Finally, but more importantly, there is a paucity of research related to the provision of palliative care in the renal setting. The significant challenges posed for nurses by this practice setting need to be urgently addressed. Medical research into renal palliative care is beginning to emerge (Cohen et al 2000; Walters et al 2000; Weisbord et al 2003) but this does not specifically deal with the needs of patients and their families. Similarly, research into the impact on nurses who are involved in ceasing life-sustaining renal therapies, also warrants investigation.

The role palliative care has to offer in non-

malignant disease is paramount and specifically, a comfortable death from ESRD following withdrawal of dialysis is achievable through the development of partnerships, inclusion of a multidisciplinary team approach and the creation of dialogue between experts. This arrangement creates the opportunity for the direct provision of palliative care services working in collaboration with a nursing specialty where little is known of the specific needs of the dying and their family, in the renal setting. Nurses play a pivotal role in the coordination of care and as such the challenge exists for renal nurses to establish partnerships and dialogue that facilitate the enhancement of knowledge and skills for transfer to the renal setting.

CONCLUSION

The renal setting warrants research that will explore and identify specifically the knowledge and skills required of renal nurses in managing the needs of the person dying and their family, following withdrawal of dialysis. The outcomes of these endeavours will see the provision of quality palliative care, informed by research, being provided to the person dying and their family. In addition, the impact on the renal nurse who participates in the withdrawal of life sustaining renal therapies will be better prepared and supported in their practice.

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